

General

Guideline Title

Occupational therapy practice guidelines for adults with neurodegenerative diseases.

Bibliographic Source(s)

Preissner K. Occupational therapy practice guidelines for adults with neurodegenerative diseases. Bethesda (MD): American Occupational Therapy Association, Inc. (AOTA); 2014. 187 p. [225 references]

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Recommendations

Major Recommendations

Note from the National Guideline Clearinghouse: In addition to the evidence-based recommendations below, the guideline includes extensive information on the evaluation process and intervention strategies for people with multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), Parkinson's disease (PD), and transverse myelitis (TM).

Definitions for the strength of recommendations (A–D, I) and levels of evidence (I–V) are provided at the end of the "Major Recommendations" field.

Recommendations for Occupational Therapy Interventions for Adults with Neurodegenerative Diseases

Multiple Sclerosis

Interventions Focusing on Activity and Participation

- Face-to-face fatigue management programs to reduce the impact of fatigue, improve quality of life (QoL), and improve self-efficacy for using fatigue management strategies (A)
- Teleconference-delivered fatigue management programs to reduce the impact of fatigue on daily life and to improve QoL (A)
- Multidisciplinary rehabilitation provided in a variety of settings to improve levels of activity and participation and health-related QoL (A)
- Outpatient rehabilitation programs for people with MS to improve health and QoL, reduce the impact of fatigue, and improve social functioning (B)
- Inpatient rehabilitation to reduce disease severity and improve activities of daily living (ADL) status (B)
- A home-based program to improve performance (B)

- Outpatient rehabilitation to improve ADL performance (B)
- Health promotion programs to improve health, increase physical activity and spiritual growth, and reduce stress (C)
- Vocational rehabilitation (I)
- Program to improve functional mobility (I)

Interventions Focusing on Performance Skills

Social Interaction Skills

- Emotion regulation interventions to improve mood, reduce levels of depression, reduce stress, and improve self-efficacy (A)

Process Skills

- Home-based, individualized, and computerized cognitive training to improve attention, memory, information processing, and executive functions (B)
- Memory training to improve memory on a short-term basis (B)

Motor Skills

- Physical activity programs to improve muscle power and mobility (A)
- Aerobic activity programs to improve walking distance, endurance, and QoL (A)
- Resistance training to improve speed and endurance (B)
- Motor training to restore neuromusculoskeletal and movement-related functions and motor and praxis skills (I)

Parkinson's Disease

Engagement in Exercise and Physical Activity to Improve Performance Skills and Occupational Performance

- Multisession, repetitive physical exercise (diachronic) to improve motor and sensory-perceptual performance skills (A or B)
- Specialized forms of exercise or more intense task-specific exercise (diachronic) to improve performance more than usual forms or less intense exercise (C)
- Single-task interventions in a single session to improve skill development (C)

Occupational Performance

- Environmental cues, stimuli, and assistive objects to improve task and occupational performance. (B)
- Auditory rhythmic external cues, which are more effective than visual, tactile, or other forms of cues, to help regulate walking in PD (B)
- Client-preferred external cues during ADLs to improve motor control (B)
- Individualized interventions focusing on participant wellness, lifestyle modification, and personal control to improve QoL (B)
- Complex and multimodal activity (e.g., tango dancing) to improve functional movement on a short-term basis (B)
- Tai chi to enhance motor and postural performance skills in PD (C)
- Multimodal physical activity to improve cognitive performance, particularly executive functioning (C)
- Avoidance of environmental cues that divide attention or focus attention away from the primary task or elicit negative emotions (D)

Amyotrophic Lateral Sclerosis

- Home exercise program of daily stretching and resistance exercise improves functional outcome with no adverse effects. (B)
- Participating in a multidisciplinary program improves survival as compared with general care. (C to B)
- A supervised exercise program to maintain functional capacity is better than a home exercise program (C)
- Participating in a multidisciplinary program results in a higher percentage of use of appropriate assistive devices and a higher QoL in social functioning and mental health than general care. (C)
- Power wheelchair (PWC) users are satisfied with ease of use and comfort, and PWCs can include tilt, recline, head, neck, trunk, and extremity supports; power elevating leg rests; ability to run power features through joystick with upgraded electronics; air or gel cushion; soft headrest; seatbelts; and height-adjustable flat, gel, or contoured armrests. (C)
- PWCs facilitate participation in activities as compared with manual wheelchairs. (C)
- Manual wheelchairs provide ease of portability as compared with PWCs. (C)
- High degrees of usefulness and satisfaction are reported for elevated toilet seat, rails by toilet, shower seat, shower bars, slip-on shoes, ankle brace, and transfer board. (C)
- High degrees of satisfaction but infrequent use are reported for sound- or voice-activated environmental controls and communication

boards. (C)

- Low degrees of usefulness and satisfaction are reported for buttonhooks, dressing sticks, and long-handled reaching tools. (C)
- Telemedicine is reported as useful and satisfying to persons with ALS, except for discussions of psychological and emotional concerns. (C)
- Using a computer program for writing messages and choosing songs and videos through a virtual keyboard and microswitch are reported as useful. (I)
- Electrical stimulation can improve bilateral hand function and knee extension. (I)
- Aquatic therapy is helpful to increase energy and reduce assistance for transfers after therapy. (I)
- Sling back and sling seats are reported to be not helpful or satisfying to wheelchair users. (D)

Note: Criteria for level of evidence and recommendations (A, B, C, I, D) are based on standard language from the Agency for Healthcare Research and Quality (2012). Suggested recommendations are based on the available evidence and content experts' clinical expertise regarding the value of using it.

Definitions:

Levels of Evidence for Occupational Therapy Outcomes Research

Evidence Level	Definitions
I	Systematic reviews, meta-analyses, randomized controlled trials
II	Two groups, nonrandomized studies (e.g., cohort, case control)
III	One group, nonrandomized (e.g., before and after, pretest and posttest)
IV	Descriptive studies that include analysis of outcomes (e.g., single-subject design, case series)
V	Case reports and expert opinion that include narrative literature reviews and consensus statements

Note: Adapted from "Evidence-based medicine: What it is and what it isn't." D. L. Sackett, W. M. Rosenberg, J. A. Muir Gray, R. B. Haynes, & W. S. Richardson, 1996, *British Medical Journal*, 312, pp. 71-72. Copyright © 1996 by the British Medical Association. Adapted with permission.

Strength of Recommendations

A—There is strong evidence that occupational therapy practitioners should routinely provide the intervention to eligible clients. Good evidence was found that the intervention improves important outcomes and concludes that benefits substantially outweigh harm.

B—There is moderate evidence that occupational therapy practitioners should routinely provide the intervention to eligible clients. There is high certainty that the net benefit is moderate, or there is moderate certainty that the net benefit is moderate to substantial.

C—There is weak evidence that the intervention can improve outcomes. It is recommended that the intervention be provided selectively on the basis of professional judgment and patient preferences. There is at least moderate certainty that the net benefit is small.

I—There is insufficient evidence to determine whether or not occupational therapy practitioners should be routinely providing the intervention. Evidence that the intervention is effective is lacking, of poor quality, or conflicting and the balance of benefits and harm cannot be determined.

D—It is recommended that occupational therapy practitioners not provide the intervention to eligible clients. At least fair evidence was found that the intervention is ineffective or that harm outweighs benefits.

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

Neurodegenerative diseases (NDDs), specifically:

- Multiple sclerosis (MS)
- Parkinson's disease (PD)

- Amyotrophic lateral sclerosis (ALS)
- Transverse myelitis (TM)

Guideline Category

Counseling

Management

Rehabilitation

Clinical Specialty

Family Practice

Internal Medicine

Neurology

Physical Medicine and Rehabilitation

Intended Users

Advanced Practice Nurses

Allied Health Personnel

Health Care Providers

Health Plans

Managed Care Organizations

Nurses

Occupational Therapists

Patients

Physical Therapists

Physician Assistants

Physicians

Public Health Departments

Social Workers

Students

Utilization Management

Guideline Objective(s)

- To provide an overview of the occupational therapy process for adults with neurodegenerative diseases (NDD), specifically multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), Parkinson's disease (PD), and transverse myelitis (TM)
- To define the occupational therapy domain and process and interventions that occur within the boundaries of acceptable practice
- To help occupational therapists and occupational therapy assistants, as well as the individuals who manage, reimburse, or set policy

- regarding occupational therapy services, understand the contribution of occupational therapy in providing services to adults with NDD
- To serve as a reference for health care professionals, health care facility managers, education and health care regulators, third-party payers, and managed care organizations

Target Population

Adult with neurodegenerative diseases (NDDs), specifically multiple sclerosis (MS), Parkinson's disease (PD), amyotrophic lateral sclerosis (ALS), and transverse myelitis (TM)

Interventions and Practices Considered

Multiple Sclerosis (MS)

1. Focus on activity and participation
 - Fatigue management (face-to-face and teleconference-delivered management programs)
 - Multidisciplinary, outpatient, inpatient and vocational rehabilitation
 - Home-based programs
 - Health promotion programs
 - Improvement of functional mobility
2. Focus on performance skills
 - Social interaction skills (emotion regulation interventions)
 - Process skills (cognition and memory regulation)
 - Exercise and motor training

Parkinson's Disease (PD)

1. Exercise and physical activity
2. Occupational performance
 - Use of environmental cues, stimuli and objects
 - Auditory rhythmic external cues
 - Individualized interventions focusing on participant wellness
 - Complex and multimodal activity (tai chi)

Amyotrophic Lateral Sclerosis (ALS)

1. Exercise (daily stretching, resistance exercise, aquatic therapy)
2. Multidisciplinary programs
3. Assistive devices and wheelchairs
4. Sound- or voice-activated environmental controls and communication boards
5. Computer programs (virtual keyboard and microswitch)
6. Electrical stimulation

Major Outcomes Considered

- Greater self-efficacy
- Reduction of disease symptoms
- Reduced levels of depression
- Quality of life (QoL)

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

The following four focused questions from the review of occupational therapy interventions for adults with neurodegenerative diseases framed the reviews:

1. What is the effectiveness of interventions within the scope of occupational therapy practice for persons with multiple sclerosis (MS)?
2. What is the effectiveness of interventions within the scope of occupational therapy practice for persons with Parkinson's disease (PD)?
3. What is the effectiveness of interventions within the scope of occupational therapy practice for persons with amyotrophic lateral sclerosis (ALS)?
4. What is the effectiveness of interventions within the scope of occupational therapy practice for persons with transverse myelitis (TM)?

Search terms for the reviews were developed by the methodology consultant to the American Occupational Therapy Association, Inc. (AOTA) Evidence-Based Practice Project (EBP) and AOTA staff, in consultation with the authors of each systematic review question, and reviewed by the advisory group. The search terms were developed not only to capture pertinent articles but also to make sure that the terms relevant to the specific thesaurus of each database were included. Table D.2 in the original guideline document lists the search terms related to population and intervention included in each systematic review. A medical research librarian with experience in completing systematic review searches conducted all searches and confirmed and improved the search strategies.

Databases and sites searched included MEDLINE, PsycINFO, CINAHL, AgeLine, and OTseeker. In addition, consolidated information sources, such as the Cochrane Database of Systematic Reviews and the Campbell Collaboration, were included in the search. These databases are peer-reviewed summaries of journal articles and provide a system for clinicians and scientists to conduct evidence-based reviews of selected clinical questions and topics. Moreover, reference lists from articles included in the systematic reviews were examined for potential articles, and selected journals were hand searched to ensure that all appropriate articles were included.

Inclusion and exclusion criteria are critical to the systematic review process because they provide the structure for the quality, type, and years of publication of the literature that is incorporated into a review. The review of all four focused guideline questions was limited to peer-reviewed scientific literature published in English. The intervention approaches examined were within the scope of practice of occupational therapy. The literature included in the review was published between 2003 and 2011 and included study participants with neurodegenerative disease (multiple sclerosis [MS], Parkinson's disease [PD], amyotrophic lateral sclerosis [ALS], transverse myelitis [TM]). The earlier reviews included studies published between 1985 and 2002. The review excluded data from presentations, conference proceedings, non-peer-reviewed research literature, dissertations, and theses. Studies included in the review are Level I, II, and III evidence. Level IV and V evidence was included only when higher level evidence on a given topic was not found.

A total of 11,672 citations and abstracts were included in the reviews. For the question on MS, there were 3,484 references; for the PD question, 4,061 references; for the ALS question, 872 references; and for the TM question, 149 references.

The consultant to the EBP project completed the first step of eliminating references on the basis of citation and abstract. All articles were eliminated from the initial TM review because none were within the scope of occupational therapy practice, and the results of the review are not discussed in the *Practice Guidelines*. The systematic reviews for PD and MS were carried out as academic partnerships, in which academic faculty worked with graduate students to carry out the reviews. The systematic review on ALS was carried out as a partnership between the AOTA methodology consultant and an occupational therapist with expertise in ALS. Review teams completed the next step of eliminating references on the basis of citations and abstracts. The full-text versions of potential articles were retrieved, and the review teams determined final inclusion in the review on the basis of predetermined inclusion and exclusion criteria.

Number of Source Documents

A total of 140 articles were included in the final review. The review included 79 Level I studies, 23 Level II studies, 33 Level III studies, 3 Level IV studies, 1 Level V study.

Methods Used to Assess the Quality and Strength of the Evidence

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Levels of Evidence for Occupational Therapy Outcomes Research

Evidence Level	Definitions
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III	One group, nonrandomized (e.g., before and after, pretest and posttest)
IV	Descriptive studies that include analysis of outcomes (e.g., single-subject design, case series)
V	Case reports and expert opinion that include narrative literature reviews and consensus statements

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Methods Used to Analyze the Evidence

Review of Published Meta-Analyses

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

The teams working on each focused question reviewed the articles according to their quality (scientific rigor and lack of bias) and levels of evidence. Each article included in the review was then abstracted using an evidence table that provides a summary of the methods and findings of the article and an appraisal of the strengths and weaknesses of the study on the basis of design and methodology. American Occupational Therapy Association Inc. (AOTA) staff and the Evidence-Based Practice (EBP) project consultant reviewed the evidence tables to ensure quality control.

All studies are summarized in full in the evidence tables in Appendix E of the original guideline document. The limitations of the systematic reviews are based on the design and methods of the individual studies, including small sample sizes, high dropout rates, and limited descriptions of the psychometric properties of outcome measures. In addition, many of the studies in the review included concurrent interventions, and separating the effects of a single intervention may be difficult.

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

A major focus of the American Occupational Therapy Association (AOTA)'s Evidence-Based Practice (EBP) projects is an ongoing program of systematic review of multidisciplinary scientific literature, using focused questions and standardized procedures to identify practice-relevant evidence and discuss its implications for practice, education, and research. An evidence-based perspective is founded on the assumption that scientific evidence of the effectiveness of occupational therapy intervention can be judged to be more or less strong and valid according to a hierarchy of research designs, an assessment of the quality of the research, or both. AOTA uses standards of evidence modeled on those developed in evidence-based medicine. This model standardizes and ranks the value of scientific evidence for biomedical practice using the grading system presented in the "Rating Scheme for the Strength of the Evidence" field of this summary. In this system, the highest level of evidence, Level I, includes systematic reviews of the literature, meta-analyses and randomized controlled trials (RCTs). In RCTs, participants are randomly allocated to either an intervention or a control group, and the outcomes of both groups are compared. Other levels of evidence include Level II

studies, in which assignment to a treatment or a control group is not randomized (cohort study); Level III studies, which do not have a control group; Level IV studies, which use a single-case experimental design, sometimes reported over several participants; and Level V studies, which are case reports and expert opinion that include narrative literature reviews and consensus statements.

The systematic reviews on neurodegenerative diseases were supported by AOTA as part of the EBP Project. AOTA is committed to supporting the role of occupational therapy in this important area of practice. Previous reviews were completed covering the time frame of 1985 to 2002. The current systematic reviews were updated for the period 2003 to 2011 because occupational therapy practitioners need access to the results of the latest and best available literature to support intervention within the scope of occupational therapy practice.

The four focused questions developed for the updated review were based on the search strategy of the earlier review. These questions were reviewed by review authors, an advisory group of experts in the field, AOTA staff, and the consultant to the AOTA EBP Project.

Rating Scheme for the Strength of the Recommendations

Strength of Recommendations

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Cost Analysis

A formal cost analysis was not performed and published analyses were not reviewed.

Method of Guideline Validation

Peer Review

Description of Method of Guideline Validation

Not stated

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for each recommendation (see the "Major Recommendations" field).

The final review included 140 articles. Studies included in the review are Level I, II, and III evidence. Level IV and V evidence was included only when higher level evidence on a given topic was not found.

Number of Articles in Each Review at Each Level of Evidence						
	Evidence Level					
Review	I	II	III	IV	V	Total in Each Review
Parkinson's disease	35	7	13	0	0	55
Multiple sclerosis	41	13	16	0	0	70
Amyotrophic lateral sclerosis	3	3	4	3	1	14
Total	79	23	33	3	1	139

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

These guidelines may be used to assist:

- Occupational therapists and occupational therapy assistants in providing evidence-based interventions to adults with neurodegenerative disease (NDD)
- Occupational therapists and occupational therapy assistants in communicating about their services to external audiences
- Other health care practitioners, case managers, clients, families and caregivers, and health care facility managers in determining whether referral for occupational therapy services is appropriate
- Third-party payers in determining the medical necessity for occupational therapy
- Legislators; third-party payers; federal, state, and local agencies; and administrators in understanding the professional education, training, and skills of occupational therapists and occupational therapy assistants
- Health and social services planning teams in determining the need for occupational therapy
- Program developers; administrators; legislators; federal, state, and local agencies; and third-party payers in understanding the scope of occupational therapy services
- Researchers, occupational therapists, occupational therapy assistants, program evaluators, and policy analysts in this practice area in determining outcome measures for analyzing the effectiveness of occupational therapy intervention
- Policy, education, and health care benefit analysts in understanding the appropriateness of occupational therapy services for adults with NDD
- Policymakers, legislators, and organizations in understanding the contribution occupational therapy can make in health promotion, program development, and health care reform to support adults with NDD
- Occupational therapy educators in designing appropriate curricula that incorporate the role of occupational therapy with adults with NDD

Potential Harms

Not stated

Qualifying Statements

Qualifying Statements

- This guideline does not discuss all possible methods of care and, although it does recommend some specific methods of care, the occupational therapist makes the ultimate judgment regarding the appropriateness of a given intervention in light of a specific person's or group's circumstances, needs, and the evidence available to support the intervention.
- This publication is designed to provide accurate and authoritative information in regard to the subject matter covered. It is sold or distributed with the understanding that the publisher is not engaged in rendering legal, accounting, or other professional service. If legal advice or other expert assistance is required, the services of a competent professional person should be sought.
- It is the objective of the American Occupational Therapy Association (AOTA) to be a forum for free expression and interchange of ideas.

Implementation of the Guideline

Description of Implementation Strategy

An implementation strategy was not provided.

Implementation Tools

Staff Training/Competency Material

For information about availability, see the *Availability of Companion Documents* and *Patient Resources* fields below.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

Preissner K. Occupational therapy practice guidelines for adults with neurodegenerative diseases. Bethesda (MD): American Occupational Therapy Association, Inc. (AOTA); 2014. 187 p. [225 references]

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2014

Guideline Developer(s)

American Occupational Therapy Association, Inc. - Professional Association

Source(s) of Funding

American Occupational Therapy Association, Inc.

Guideline Committee

Not stated

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Financial Disclosures/Conflicts of Interest

The authors of this Practice Guideline have signed a Conflict of Interest statement indicating that they have no conflicts that would bear on this work.

Guideline Status

This is the current release of the guideline.

This guideline meets NGC's 2013 (revised) inclusion criteria.

Guideline Availability

Electronic copies: Not available at this time.

Print copies: Available for purchase from The American Occupational Therapy Association (AOTA), Inc., 4720 Montgomery Lane, Bethesda, MD 20814, Phone: 1-877-404-AOTA (2682), TDD: 800-377-8555, Fax: 301-652-7711. This guideline can also be ordered online at the [AOTA Web site](#) .

Availability of Companion Documents

The following are available:

- Occupational therapy practice framework: domain and process. 3rd ed. 2014. Available to order from the [American Occupational Therapy Association, Inc. \(AOTA\) Web site](#) .
- The role of occupational therapy in chronic disease management. Fact sheet. Bethesda (MD): American Occupational Therapy Association, Inc. (AOTA). 4 p. Electronic copies: Available from the [AOTA Web site](#) .

In addition, case studies are available in the original guideline document.

Patient Resources

None available

NGC Status

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